DOCUMENT RESUME

ED 412 680 EC 305 878

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TITLE	Standing with People in Support, Not Control: Training toward Self-Reliance, Inc. Sacramento, CA.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	1997-03-00
NOTE	26p.
CONTRACT	H133D50037
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Adults; *Agency Role; *Developmental Disabilities; *Helping Relationship; Housing Needs; *Independent Living; *Multiple Disabilities; Parents with Disabilities; Personal Autonomy; *Self Management
IDENTIFIERS	*Personal Assistance (of Disabled)

ABSTRACT

This report describes a program designed to increase opportunities for people with developmental disabilities to lead good lives in places of their own, strengthen their communities, and enjoy a genuine sense of self-worth. In addition to offering independent services, the Training Toward Self-Reliance (TTSR) program staff have increased their capacity and commitment to support people with multiple disabilities or those who need more intensive levels of support than those typically offered through independent living services. Services provided include helping people get their own homes or apartments, helping people arrange and manage personal assistance and other in-home supports, and assisting people to develop social relationships and networks. Expertise has been developed in supporting parents who themselves have disabilities, supporting adults with developmental disabilities to manage their own personal assistance services, and supporting people with disabilities whose lives have been substantially affected by social problems associated with poverty, substance abuse, and interpersonal turmoil. The first section of the report describes supports provided by TTSR to a few individuals who are representative of many others supported by the agency. The second section discusses key values that determine agency response and strategies that TTSR uses to provide services that support, not control, individuals with developmental disabilities. (CR)

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SACRAMENTO, CA

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STANDING WITH PEOPLE IN SUPPORT, NOT CONTROL:

TRAINING TOWARD SELF-RELIANCE, INC.

SACRAMENTO, CA

by Pam Walker

March 1997

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The preparation of this report was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred.

STANDING WITH PEOPLE IN SUPPORT, NOT CONTROL:

TRAINING TOWARD SELF-RELIANCE, INC.

SACRAMENTO, CA

Pam Walker

March 1997

The purpose of Training Toward Self-Reliance, Inc. (TTSR) is "to increase opportunities for people with disabilities to lead good lives in places of their own, strengthen their communities, and enjoy a genuine sense of self-worth." TTSR was founded in 1982 to support people with developmental disabilities in the Sacramento area, within the 10-county Alta California Regional Center district. The agency supports about 170 people, with a commitment not to exceed 175. Agency staff include 17 community support facilitators, 2 associate directors, the executive director, office staff, and a number of part-time personal assistants.

The state of California established the regional center system in the 1970s as a vehicle to provide community services. The 21 contiguous regional centers are private, nonprofit agencies that determine client eligibility, provide case management, and purchase services for people with developmental disabilities. These include residential services (which range from traditional independent living services, typically for people with less severe disabilities, to small- and large-group residential settings for

people with more severe and multiple impairments), day programs, transportation, family support, recreation, and others.

Over time, TTSR has evolved in two key ways. First, while the agency has offered independent living services since its inception, over the years, agency staff have increased their capacity and commitment to support people who have multiple disabilities or who need more intensive levels of support than those typically offered through independent living services. Second, the focus of agency supports used to be primarily on goal-directed, time-limited skills training. While such supports are still offered, staff at TTSR currently provide a much broader range of supports (e.g., helping people get their own homes and apartments, helping people arrange and manage personal assistants and other in-home supports, assisting people to develop social relationships and networks) based on each person's needs and desires, on an ongoing, indefinite basis.

Accompanying these changes, and over the course of time, TTSR staff have developed particular expertise in three areas: 1) supporting parents who themselves have disabilities; 2) supporting adults with developmental disabilities to manage their own personal assistance services (PAS); and 3) supporting people with disabilities whose lives have been substantially affected by social problems associated with poverty, substance abuse, and interpersonal turmoil. This report describes some of the supports provided by TTSR and discusses related service system issues.

Supports Provided by TTSR

This section describes supports provided by TTSR to a few individuals who are representative of many others supported by the agency. As previously noted, TTSR staff have placed particular focus on support of people who have many other problems in their lives in addition to disability; support of parents with developmental disabilities; and support for people with developmental disabilities to manage personal assistance services. Examples of each are described below. However, people do not fit into such distinct support categories; thus, a given individual may at the same time be a parent, have many difficult life circumstances, and manage his or her own personal assistants.

Support to People who are Vulnerable to Social Problems: Grace

TTSR supports a number of individuals who are very vulnerable to abuse, homelessness, addiction, and so on. Other agencies won't serve or have given up on some of these people.

Over the course of her lifetime, Grace has experienced a tremendous amount of rejection and abuse. As a child, she was adopted; currently, she has very limited contact with her adoptive family and indicates that they are not supportive of her. She has at different times been homeless, involved in prostitution, used drugs, and

been in abusive relationships. Grace, who is 32 years old, is labeled as having mild mental retardation and a severe seizure disorder.

She has a representative payee at the regional center who sends her $20 per week for spending money out of her Supplemental Security Income (SSI) check. From her spending money, Grace regularly sends a contribution to help support a child through Children International. She adds, "My parents swore at me when they found out."

Currently, Grace lives with her boyfriend, Thomas, in a small, sparsely furnished apartment. She spends time with her TTSR support worker, Alison, at least twice a month, with additional contact by phone or in person when needed or desired. Alison has supported and encouraged Grace as she has made changes in a number of areas of her life--areas in which Grace has requested assistance. For example, Grace has decided she would like to try surgery to decrease her frequent seizures. This has generated significant fear and anxiety for Grace, and Alison has supported her through this process, including accompanying her to doctors' appointments in preparation for this surgery. Alison has assisted Grace to do such things as learn bus routes, or to go shopping for clothing and other major items at times when she needs to "spend down" her SSI accumulation.

As their relationship has developed, Alison has been able to make various suggestions that have had a significant influence on Grace's life. For instance, Alison

gave Grace the idea of keeping a list on a pad of paper that she carries with her as a reminder of errands and other things she needs or wants to do. Grace now uses such a list, checking it periodically, crossing out some items and adding others. In addition, Alison has helped Grace devise strategies for keeping track of her daily medications.

Grace enjoys being a regular at two neighborhood coffee shops. However, she was informed that some patrons of one of these coffee shops had complained about her personal hygiene. Alison has worked with Grace to increase the frequency with which she takes showers and does her laundry. Despite isolated complaints, Grace is still known and welcomed by most people at these coffee shops. She does some typing on a small typewriter that she has at home for the manager of one of the restaurants. After her surgery, she would like to do more typing for others, perhaps as a small business venture. At Thanksgiving, a waitress in one of the diners bought her a Thanksgiving dinner. Grace has difficulty accepting this as a gift, and talks about hoping to repay her one day.

When asked about her relationship with staff at TTSR, Grace contrasts them with staff at past residential settings: "I used to live in a 54-bed board and care; staff there used to call the police on me." She feels that staff at TTSR are her allys.

Support of Parents with Special Needs: Liz

TTSR supports approximately 40 people with developmental disabilities who are also parents. One such person is Liz, the mother of 6-year-old Tim. Liz has been labeled as having cerebral palsy and mild mental retardation. Tim's father (Paul) died when Tim was 2. Liz first began receiving support from TTSR prior to Paul's death, during a time when he was incarcerated. Then, after Paul's death, Liz requested further assistance. From her perspective,

> We had been living in hotels. TTSR was real supportive when Paul died. It was the first time I was on my own. I had to move. TTSR helped me find an apartment, get a payee. Most of my son's life I slept in the living room. Now I have a two-bedroom apartment.

Liz receives support from a variety of different sources. She has a case manager through the regional center and a community support facilitator through TTSR; she is on welfare and SSI; she has a Section 8 housing voucher; and she receives 53 hours per month of personal assistance services, primarily for cleaning and laundry.

Within the state of California, personal assistance services are obtained through the state's In-Home Support Services (IHSS) program (see a further description of this program on p. 8). Liz obtained her own assistants through a list supplied by

IHSS. However, she said that Kris, from TTSR, has helped her deal with problems that she has had with her assistants. For instance, Liz was signing blank time sheets and her assistant was later filling in more hours than she was working. Liz reflected:

> I knew I wanted to fire her. But, I wasn't emotionally ready for confrontation. TTSR helped give me the strength to fire her.

Liz and her assistants have sometimes experienced conflict and confusion over their roles, with Liz's desire in some cases to have a new friendship as well as an assistant. Kris is supporting Liz to balance and negotiate her relationships with assistants. Liz also feels that the personal assistant management course offered by TTSR at a local community college was helpful to her.

With reference to Kris's role in supporting her, Liz comments:

> I know she wants things in my best interest, not hers. If I make a decision she thinks is not in my best interest, she'll get in my face. But, she also respects my decisions.

Kris has reported Liz to Children's Protective Services for bruises on Tim after Liz hit him. Kris is always direct with Liz about when and why she is doing this.

Overall, Liz said she considers the agency "as family" to her. Other than this, she describes herself as having no other support system. She has relatives who live elsewhere in the state, but she only sees them every few years and doesn't consider

them to be very supportive of her. At the same time, part of Kris's role involves assisting Liz to expand her support network. Liz has found some support from staff members at Tim's school. In addition, she has participated, off and on, in various support groups, including AlAnon and Families Anonymous. Overall, Liz appreciates that staff from TTSR have not tried to control her, but instead have assisted her to become more self-sufficient and a better parent.

Support to People to Manage Personal Assistants

TTSR supports a number of people with developmental disabilities to manage their personal assistance services (PAS). In California, PAS are provided through counties, via the In-Home Supportive Services (IHSS) program. This program is funded through both state and federal dollars. To be eligible, an individual must have a disability. People whose income does not exceed the SSI level pay no "share of cost" for their IHSS. Those accepted for the program include people with a wide range of ages and disabilities, including some individuals with developmental disability labels. A person can receive up to the maximum of 283 hours per month of support. Within this program, people with disabilities are the managers of their own supports, responsible for recruiting and managing their assistants. TTSR assists people with developmental disabilities who use PAS--funded by IHSS, the regional center, or

both--to be effective employers of their assistants. A few situations are described briefly below.

Rob. In the past, Rob, who has severe cerebral palsy and uses a wheelchair, has lived in various group homes and intermediate care facilities. Now he lives in his own apartment, with 99 hours of personal assistance per month. Rob pursued this quest to attain more control of his life over the protests of his father and the eventual severing of that relationship. As Rob describes it, "My father was my guardian; but, he wanted to control me." Rob went to court and was judged competent. The trust fund that his father had established for Rob was liquidated. With the money, Rob purchased a van. His assistants drive the van for him. In addition, they help with other household tasks such as cooking and cleaning.

Scott, a facilitator from TTSR, has provided Rob with support in managing his personal assistance services. Scott helped Rob place ads in the newspaper, and write a job description. Rob asked Scott to screen applicants; then, Rob conducted interviews, using TTSR office space. Scott and Rob have worked together to create a weekly schedule for assistants.

One of the people who Rob has hired as an assistant is a man with a disability, also supported by TTSR, who lives in the same apartment complex. Because of this proximity, this man can provide back-up support if another assistant does not show up or if an emergency arises. In addition, Rob's back-up support system includes his

case worker from the regional center, Scott from TTSR, and an uncle and aunt who are supportive of him.

Betty and Don. Betty and Don have been married for 11 years. They rent a small house and have PAS support for approximately 2 hours per day to assist with cleaning and cooking. Betty, who is blind and has mild developmental disabilities, works at a sheltered workshop; Don, who has some visual impairment and moderate developmental disability, does volunteer work at the Society for the Blind. Neither have very much contact with family members, though Betty regularly visits her mother who is in a nursing home.

They have a case manager from the regional center, who contacted TTSR and asked them to get involved after she suspected that one of their attendants was stealing from them. Both Don and Betty indicated that the support from TTSR has been helpful in terms of assisting them to deal with problems with attendants. In addition, Betty said that the attendant management course offered by TTSR was very helpful to her.

Steve. Steve has his own apartment in a small complex located on the edge of the city, where he prefers to live. Of his past, he comments:

> My family was cruel. I don't have any contact with them.
>
> They put me in a nursing home. I was there for 8 years.

Eventually, a staff member who became a friend helped him move out.

Steve, who uses a wheelchair, receives 250 hours per month of attendant care services. Initially, the nursing home staff member who helped him move became an attendant. He has had other attendants who have become friends and have moved in with him, and then moved out. TTSR assists him in dealing with relationships with attendants. In addition, TTSR staff members have helped him arrange doctors' appointments and have participated in SSI meetings with him.

Steve spends much of his free time on his computer. He got it with funds provided through the regional center. With it, he communicates with friends, and recently designed a flyer advertising a business he would like to start--assisting others to recruit attendants. In the future, he would like to take some computer classes. In addition, he is hoping to get a job working for Easter Seals.

Service System Issues: Experiences and Lessons from TTSR

Based on the experiences of agency staff, there are lessons that can be drawn related to service system issues that are critical considerations for many other agencies. At TTSR, values have played a central role in determination of agency responses to service system issues. Key values include:

1. Their desire to provide services that do not control and manage people, but rather to provide supports that assist people to have maximum control over their own lives;

2. Their desire to assist people to have quality lives in the community;

3. Their effort to focus on providing high quality supports, versus serving greater numbers of people;

4. Their focus on acquiring increased competency, enabling them, in part, to provide more preventive services and less crisis intervention;

5. Their commitment to assist people to have unpaid supports and social networks, rather than only paid supports.

These values have shaped their response, in particular, to three critical issues: 1) lack of support for people with developmental disabilities to manage their own personal assistance services; 2) lack of support for parents with developmental disabilities to raise their children; and 3) service system control of people. Each issue, as well as agency responses, is discussed below.

Personal Assistance Management Support

Personal assistance services and people with developmental disabilities. TTSR staff support approximately 35 individuals with developmental disabilities in management of personal assistance services (PAS). Across the country, PAS have been utilized primarily by people with physical disabilities but not developmental disabilities. In some instances, people with developmental disabilities would not be eligible for such services (e.g., if they were considered to be not "self-

directing"); in other cases, people with developmental disabilities may receive such services, but with no support for management of these services, leaving them vulnerable to exploitation and abuse; and, in some cases, people with developmental disabilities might receive PAS through an agency which takes control, thereby leaving the person with minimal authority over who comes to work for them.

In California, people with developmental disabilities are eligible to receive PAS. The way this program works for anyone who is eligible is that the county sends someone to evaluate the person's needs; based on this, the number of hours of PAS are determined. The individual is the employer, and he or she receives authorization to hire assistants. The county has a list of possible people to recruit as attendants; however, this list is not screened for quality employees. Many people have trouble negotiating all of these arrangements. People who have developmental disabilities may be particularly vulnerable to having problems with this. Therefore, TTSR has devoted significant effort to support people to manage their PAS. Following are some of the lessons based on their experience.

<u>There is a significant degree of mistreatment of people with developmental disabilities who use PAS</u>. In the experience of staff at TTSR, mistreatment is a big issue, with too many people being taken advantage of in one way or another by assistants. In response to this, TTSR has developed its capacity to support people who use PAS in a variety of ways. This support has helped to reduce or eliminate

some of these problems for the people they support. In addition, the agency is often contacted by other service providers to come in and provide support when abuse or mistreatment is identified or suspected. As one staff member put it, "The reality is, this (dealing with mistreatment) is a way of life for lots of people who use these services." Yet, they have found that this is rarely discussed among human service providers. As another TTSR staff person commented:

> We have to work to understand how to sustain the autonomy aspect and still acknowledge that there are risks involved when you hire somebody to come into your home; that's really got to be confronted and managed, rather than just swept under rug.

They strongly feel that the risks should not be used as an excuse to take away autonomy and control, but rather, that people should receive assistance to deal with it.

A broad range of supports should be offered to assist people with developmental disabilities to manage PAS. TTSR offers a broad range of support, based upon individual need and desire. As the director put it: "Our role is to stand beside the person and assist him or her in this process."

TTSR began involvement in personal assistance service management support approximately 10 years ago. After a few years, they wrote a grant proposal in order to explore the issues.

> We were trying to develop more capacity to head problems off--not just run after problems all the time. Also, not to assume that any package of support is going to guarantee prevention of problems with assistants. What we were really trying to do is substantially reduce the odds of problems. And it's really worked well.

TTSR now operates a course on personal assistance service management at a local community college. In addition, staff members provide support to people to manage their personal assistants on an individualized and ongoing basis. They have assisted people with recruitment, and have become less dependent on the county lists and more creative about seeking out candidates from people's social networks. Staff also assist people with back-up plans; help them acquire technological adaptations, such as specialized emergency communication capacities; and help people work out the specifics of job descriptions, schedules, and supervision of assistants.

It is important to be prepared to offer support to people in negotiating relationships with assistants. Staff from TTSR frequently assist people in working out personal relationships with assistants. As one staff member described: "Friendships and complications do evolve. A lot of the people we see are so lonely, that fulfilling that loneliness is what they want in a person, that's one item on their job descriptions." TTSR staff don't assume that friendships will evolve; they take the

approach that this is an employment relationship. If and when a personal relationship does arise, however, they will assist the person in negotiating it, if desired.

TTSR has been very cautious and hesitant about becoming an employer of assistants. Currently, money for employment of assistants for 10 individuals is funneled through TTSR. This arrangement--part of their supported living services--has enabled these individuals to receive additional hours of support, above and beyond what IHSS allows. But, on the whole, the agency has opted to co-manage assistants only in a small number of exceptional situations. According to the director,

> We've been incredibly reluctant to get into the assistant hiring business, because it seems to change our relationships with the participant. The perspective really shifts when the assistant is your agency's employee, and you have two responsibilities, and two obligations, and you've got to keep the employee in mind, and that might be contrary to the preferences of the person who's using that person.

Overall, while the people they support to manage PAS still occasionally experience problems such as personality conflicts with assistants, or assistants who leave on short notice, they rarely experience significant financial exploitation or other

types of mistreatment and abuse. As one staff member put it, "Sometimes, if people know we are involved, they're far less likely to take advantage of a participant."

Support for Parents with Developmental Disabilities

Traditionally, within the service system, there has been the assumption that people with developmental disabilities are incapable of parenting. Most often, their children are automatically removed from the family. Since 1986, TTSR staff have provided support to parents with disabilities. Currently, they support approximately 40 parents. Some of the lessons they have learned include the following:

When parents with developmental disabilities are charged with child abuse or neglect, this is primarily inadvertent rather than willful harm. Often, TTSR staff first come into contact with parents with disabilities after they have experienced difficulties and, often also, after they have had some kind of involvement with Children's Protective Services. Based on their experience, staff feel that this stems primarily from inadvertent rather than willful harm. As a consequence, they feel that it is crucially important to offer instruction in various aspects of childcare and household management. TTSR facilitators operate without a routine curriculum; instead they use resource tools adapted to meet the needs of a specific family. They strive to identify and begin working with parents when they first learn they are expecting a child. In

addition, agency staff have supported a number of parents who have cognitive limitations but who do not have a developmental disability label.

It is important to offer ongoing supports, rather than only time-limited supports. In the past, the agency's services to parents were time-limited, tapering off over an 18-month period. Now, they offer the option of ongoing support. This is based on their recognition that many families have difficulties or limitations that are not likely to be resolved through instruction. In addition, they feel that societal factors--such as poverty, isolation, lack of available resources and supports, domestic violence--create some situations which call for ongoing rather than time-limited assistance.

It is important to connect families with as many community resources as possible. While TTSR staff assist families to obtain human service supports that they are eligible for (e.g., in-home services, respite, etc.), they place emphasis on developing and expanding people's connections to community resources. TTSR facilitators work exclusively in families' homes and in the community, rather than in a facility-based program. They support parents in their communication with school personnel and other professionals; they encourage participation in parent support groups; and they assist in facilitating the participation of the children in various recreational programs, Big Brother/Big Sister organizations, and the like.

Across all their efforts to support parents with developmental disabilities, the child's welfare is the primary concern. Within this context, the agency's goal is to provide opportunities and resources that enable parents with disabilities to succeed in their role as primary caregiver and to gain in self-reliance and self-assuredness as they raise their families.

Service System Control of People

Traditional service systems across the country have predominantly controlled people with developmental disabilities. This was particularly true with institutions, but has also extended into community based services and supports. In California, as in other states, there has been an effort to improve the quality of community services. For instance, "supported living" settings have decreased in size, with many for one or a few individuals. In addition, the 1992 revision of the state's Lanterman Act mandated the use of person-centered planning for individuals with developmental disabilities. While these are well-intentioned steps, they do not by any means eliminate the tendency of the service system to control people, particularly those with more severe disabilities. As one staff member put it, "There can still be a presumption of management in supported living services. Management can still be the overriding theme."

As an alternative, TTSR has a commitment not to be involved in controlling people. This value, or commitment, drives the agency's decisions regarding support strategies.

The agency has avoided participating in the provision of "supported living services" that control people's lives. As an agency, TTSR has made a decision not to get into the business of providing "supported living services" characterized by control or supervision. At the same time, they are committed to supporting people who need high levels of support. Along these lines, agency staff collaborate with some other agencies to support people who need intensive levels of support. However, they are cautious about who they collaborate with, so as to avoid collaboration with others who want to control people. In addition, they recognize the importance of combining both formal and informal, paid and nonpaid sources of support. This is noted in the agency's 1996-1999 mission and direction statement:

> We need to strengthen our capacity to help people expand their social networks and circles of support to ensure that the extra "support" people receive does not come exclusively from paid service providers.

Agency staff devote significant time and attention to maintaining each person-centered planning effort as a creative, unique, nonroutinized process. Within a context where person-centered planning is mandated, there is particular danger that it

becomes a routinized process applied in haste across many individuals. TTSR has made an effort to ensure that this does not occur within the agency. The have used an outside consultant to give additional ideas and strategies for selected planning sessions. And, they spend time together as a staff discussing and brainstorming creative, individualized responses, one person at a time.

Agency staff have made increased efforts to assist people to form and/or expand community connections and social networks in order not to be primarily reliant on agency staff for social support. They recognize their limitations, as part of the service system, in providing social support for people. While staff put significant effort into cultivating close relationships, these are still paid relationships, many of which end due to funding changes, staff turnover, and the like. Thus, one of the priorities for staff is to try to assist people to establish other, nonpaid, potentially long-term relationships.

Conclusion

A key strength of this agency is their values, and their commitment to making service decisions based upon these values. The agency supports many people who other agencies won't serve or have given up on. Agency staff stand by people through many ups and downs in their lives. They do so based on an attitude that, "Failure is impossible" (Susan B. Anthony). They refuse to see these ups and downs as a failure

on the person's part. They see success, for people they support, based on the perspective of the individual him- or herself; and not necessarily as attaining problem-free lives, but as acquiring new awarenesses, experiences, outlooks, competencies, and so forth. For staff themselves, success is doing their job well. Doing their job well is not about controlling people or forcing people to change; it is about building trusting relationships through which they can assist in enhancing people's quality of life and it is about maintaining their commitment to treat people with full respect and dignity. In this way, staff at TTSR have been a critical source of influence and support in many people's lives.

Note: This report is based on a site visit to TTSR in December, 1995. All names throughout the report are pseudonyms.

Appreciation is expressed to, Charles Galloway, Executive Director, and Sharon Fallis, Associate Director, for their assistance in preparation of this report.

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